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Knowledge, attitude, and practice of epilepsy in rural Sri Lanka

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Knowledge, attitude, and practice in relation to epilepsy in developing countries appears to be different from that in developed countries. This study was conducted to evaluate knowledge, attitudes, expectations, sociocultural aspects, patient characteristics, disease characteristics, pattern of drug therapy, and outcome of patients with epilepsy in rural Sri Lanka. Data were collected from 207 patients attending an epilepsy clinic. In general the study shows a positive trend in knowledge, expectations and attitude toward epilepsy. Social morbidity is reported from 53.6% indicating that public attitude towards epilepsy needs to be changed. Alternative modes of treatment have been tried by 45.9%, reflecting the cultural beliefs in the society. 75% are on monotherapy and carbamazepine is the most commonly used drug. Seizure control is excellent (no seizures during the preceding 6 months) in 33.8%. Side effects of antiepileptic drugs are reported by 76.3%. Various kinds of medical morbidity have been experienced by 32.9% of patients.

Key words: epilepsy; knowledge, attitude, and practice; developing countries.

INTRODUCTION

Epilepsy has a higher incidence in developing countries than in developed countries[1]. Studies from the developing world indicate that misconceptions and negative attitude toward epilepsy are still prevalent among the general public[2,3]. Furthermore, patient characteristics, disease spectrum and pattern of drug therapy can also be different in those countries. For example, age-specific prevalence rates seem to show a different pattern in developing regions[3,4]. Epidemiological studies also show a different disease spectrum in the tropical regions[5]. With that background, this study was designed to evaluate knowledge, attitude, expectations, sociocultural aspects, patient characteristics, disease characteristics, pattern of drug therapy, and outcome of patients with epilepsy in rural Sri Lanka, a country representative of the developing world.

SUBJECTS AND METHODS

The study was conducted in the epilepsy clinic at Ratnapura General Hospital which caters to a rural population in Sri Lanka. All patients with epilepsy who sought treatment over a period of three months from 01.11.2000 to 31.01.2001 were recruited to this study. Both new and follow-up patients were included. Informed consent was obtained from all. Data were collected from clinic records and by personal interview using a questionnaire.

RESULTS

A total of 207 patients were interviewed. Their ages ranged from 12 to 73 years. There were 114 (55%) males and 93 (45%) females. Seven (3.4%) were illiterate. School education up to or below grade 10 was reported in 178 (86%), whereas 21 (10.1%) had made it to the advanced examination level. Only one had received university education. Most of the patients (112; 54.1%) were unemployed, while only 4 (1.9%) had white-collar jobs (Table 1).

Their knowledge was assessed by asking the question, what is epilepsy? In 108 (52.2%) the answer was ‘do not know’, while 86 (41.5%) identified it as a disorder of the nervous system. 13 (6.3%) attributed it to evil spirits and supernatural causes.

Table 1: Characteristics of patients.

Characteristics	Number of patients	Percentage
Gender		
Male	114	55
Female	93	45
Age groups		
10–30	124	59.9
31–50	64	30.9
51–70	17	8.2
>70	2	1
Level of education		
Illiterate	7	3.4
Up to or below grade 10	178	86
Up to A/L exam	21	10.1
University education	1	0.5
Occupation		
Unemployed	112	54.1
Manual labourers	36	17.4
Farmers	9	4.4
Businessmen	18	8.7
White-collar jobs	4	1.9
Schooling	28	13.5
When was treatment sought?		
After the 1st fit	101	48.8
After the 2nd fit	21	10.2
After the 3rd fit	17	8.2
After the 4th fit	6	2.9
After the 5th fit	5	2.4
After 6 or more fits	57	27.5

Table 2: Characteristics of epilepsy.

Characteristics	Number of patients	Percentage
Aetiology		
Febrile fits	44	21.3
Head injury	43	20.8
Birth asphyxia	4	1.9
Central nervous system infections	3	1.4
Stroke	1	0.5
None identified	112	54.1
Family history of epilepsy		
Present	23	11.1
Absent	184	88.9
Precipitating factors		
Breaking sleep	103	49.8
Mental stress	67	32.4
Physical exertion	38	18.4
Fasting	21	10.4
Alcohol	13	6.3
Menstruation	9	4.3
Cold weather	3	1.4

To quantify the attitude toward epilepsy, subjects were asked to express their opinion on social stigma, quality of life, rights, and marriage of epileptics. 62 (30%) were of the view that there was social stigma attached to epilepsy. The majority believed that they could lead a normal life (166; 80.2%), and have equal rights in society (205; 99%). 112 (54.1%) said that they should get married like any non-epileptic person.

Table 3: Pattern of drug therapy.

	Number of patients	Percentage
Number of drugs used		
Monotherapy	156	75.4
Two drugs	38	18.3
Three drugs	13	6.3
Which drug?		
Carbamazepine	100	48.3
Phenytoin	68	32.9
Sodium valproate	66	31.9
Phenobarbitone	23	11.1
Clobazam	7	3.4
Clonazepam	7	3.4

Table 4: Outcome.

Parameter	Number of patients	Percentage
Seizure control(preceding 6 months)		
Excellent (no fits)	70	33.8
Good (occasional fits)	77	37.2
Reasonable (1 fit per month)	28	13.5
Bad (>1 fits a month)	32	15.5
Medical morbidity		
Abrasions and lacerations	38	18.4
Head injury	21	10.1
Fractures	7	3.4
Drowning	6	2.9
Burns	4	1.9
No morbidity reported	139	67.1
Side effects of drugs		
Sedation	90	43.5
Increased appetite	67	32.4
Hair loss	54	26.1
Loss of appetite	29	14
Gum hypertrophy	22	10.6
Skin rash	11	5.3
Gastritis	11	5.3
Headache	5	2.4
Body aches and lethargy	9	4.3
Tremors	1	0.5
No side effects reported	49	23.7

Patients were questioned about their expectations of outcome. The majority (147; 71%) expected epilepsy to be completely curable while 30 (14.5%) believed it was controllable though not fully curable. Only nine (4.4%) thought it was incurable. The answer was ‘do not know’ for 21 (10.1%).

Various alternative modes of treatment such as aurveda, homeopathy, acupuncture, and spiritual healing methods either alone or in combination had been tried by 95 (45.9%). Out of them, 86 (41.5%) had resorted to spiritual healing methods. 39 (41%) had tried those before, and 56 (59%) while, taking western medicine. 37 (39%) did so because of strong faith in those methods and 26 (27.4%) on others’ recommendations. Reasons given by the rest included lack of awareness or faith in western medicine, fear of side effects, and poor response to drugs.

Their social morbidity was assessed by several parameters. 40 (19.3%) had to stop schooling due to

Table 5: Assessment parameters used and trends seen in the sample.

Assessment parameter	Trend	Percentage of patients
Knowledge–'What is epilepsy?'		
Disorder of the nervous system	Basic understanding	41.5
Attitude		
No social stigma attached to epilepsy	Positive attitude	75.8
Epileptics can lead a normal life		
Epileptics have equal rights		
Epileptics should get married		
Expectations		
Epilepsy is completely curable	Positive expectations	85.5
Controllable though not fully curable		
Use of alternative modes of treatment	Same	45.9
Social morbidity		
Stopped schooling	Presence of social morbidity	53.6
Disturbed schooling		
Job loss		
Divorce		
Marital disharmony		
Breaking down of relationships		
Discrimination by others		

epilepsy whereas 43 (20.8%) experienced significant disturbances in schooling. Only one had a divorce and none reported marital disharmony or breakdown of relationships due to epilepsy. 31 (15%) had lost jobs due to their illness. Only 13 (6.3%) had experienced discrimination. Overall 111 (53.6%) reported to have social morbidity as reflected by parameters mentioned above either alone or in combination.

Aetiology of epilepsy could not be found in about one-half of patients. The commonest aetiological factors reported were febrile fits and head injury. Positive family history of epilepsy was found in about one-tenth. Patients' subjective perceptions of precipitating factors of seizures were assessed. The majority reported sleep deprivation and mental stress (Table 2).

The analysis of pattern of drug therapy revealed that the majority were on monotherapy. The most frequently used drug was carbamazepine followed by phenytoin and sodium valproate (Table 3).

The outcome of the sample was assessed by three parameters; seizure control during the preceding six months, medical morbidity, and side effects of drugs (Table 4). Seizure control was arbitrarily classified to be excellent if there were no fits during the six month period, good if there were only occasional fits, reasonable if there was one fit a month, and bad if more than one fit a month. According to that scheme, seizure control was found to be excellent in about one-third. Some form of medical morbidity was reported by 36.7% of patients, and head injuries due to epilepsy constituted about one-tenth of cases. Side effects of antiepileptic drugs were reported by 76.3%.

DISCUSSION AND CONCLUSIONS

This study shows a healthy trend among patients with epilepsy in regard to their knowledge, expectations, and attitude (Table 5). However, a significant percentage still resort to alternative modes of treatment. In that group the majority have tried religious and spiritual healing methods, reflecting the traditional thinking and beliefs in the rural society. Over 50% have some form of social morbidity, indicating that the attitude of the general public toward epilepsy needs to be changed. Despite that, divorce, marital disharmony, and the breakdown of relationships seem to be extremely rare. This probably reflects the strong intra-family relationships and family support found in Sri Lankan society, particularly in rural areas. It is an encouraging finding, which could be of help in the management of these patients.

About 75% are on monotherapy which is comparable to 76% reported from Scotland[6] and 61.04% from Taiwan[7]. Patterns of drug therapy also appear to be similar to the study from Scotland—carbamazepine, phenytoin, and sodium valproate being the most frequently prescribed drugs[6].

Seizure control appears to be satisfactory, with only 15.5% belonging to the poorly controlled group. This is comparable to 13% of refractory epilepsy reported from Singapore, a developed Asian country[8]. However, some form of medical morbidity due to epilepsy was reported by about one-third of patients. This could well be an underestimate due to under-reporting. At least part of that morbidity, such as burns

and drowning, could be preventable. Seizure-related burns have been caused by bottle lamps used to light homes with no electricity in rural areas and by falling into fire during cooking using firewood. It stresses the importance of taking prophylactic measures and providing better health education to patients.

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